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# Policy Priorities for the 2019 Nevada Legislative Session

**Experience Based Informed Choice For All!**

## **The Nevada Governor's Council on Developmental Disabilities**

Engaging in advocacy, system's change and capacity building activities for people with developmental disabilities and their families in order to promote equal opportunity, self-determination, and community inclusion.

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## INTRODUCTION

The Nevada Governor's Council on Developmental Disabilities (NGCDD) is authorized in accordance with Public Law 106-402 of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and established under NRS 232.320 within the State of Nevada.

The Act defines a developmental disability as a severe, chronic disability that is attributable to a mental or physical impairment or a combination of mental and physical impairments; manifests before age 22; is likely to continue indefinitely and results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

The purpose of the Council, as defined by statute, is to engage in advocacy, capacity building, and systemic change activities that contribute to a coordinated, consumer and family directed, comprehensive system of community services, individualized supports, and other forms of assistance that empower individuals with intellectual and developmental disabilities (I/DD) to exercise self-determination, be independent, productive, integrated and included in all facets of community life. Key activities include training and technical assistance to individuals with I/DD, families, and service providers, bringing together businesses, service providers, agencies, policy-makers, and community groups to find solutions to persistent problems, developing and testing innovative new programs and service models and most importantly, bringing the voices of individuals with I/DD to the policy-makers whose decisions impact their lives. The Policy Priorities outlined in this report represent the voices of those with I/DD and their families in Nevada.

DD Councils are designed to be operated by and for the developmental disability community. Council members are appointed by the Governor and include individuals with I/DD; parents or family members of individuals with I/DD; and individuals who represent agencies that provide services to people with I/DD. Sixty percent (60%) of the Council is comprised of individuals with I/DD and/or parents/caregivers of individuals with I/DD.

The balance of the Council is composed of representatives from agencies that administer programs that provide services to people with disabilities and include: the Rehabilitation Act, IDEA, the Older Americans Act, Title V and XIX of the Social Security Act, the Protection and Advocacy agency and the University Center for Excellence. One non-governmental provider agency is also represented.

### FIVE YEAR STATE PLAN

Council strategies and activities are based on a comprehensive review and analysis of needs, services and supports for individuals with I/DD in Nevada. Those findings are incorporated into our Five Year State Plan based on Federal “Areas of Emphasis” as outlined in the DD Act. Findings from our current Five Year State Plan.

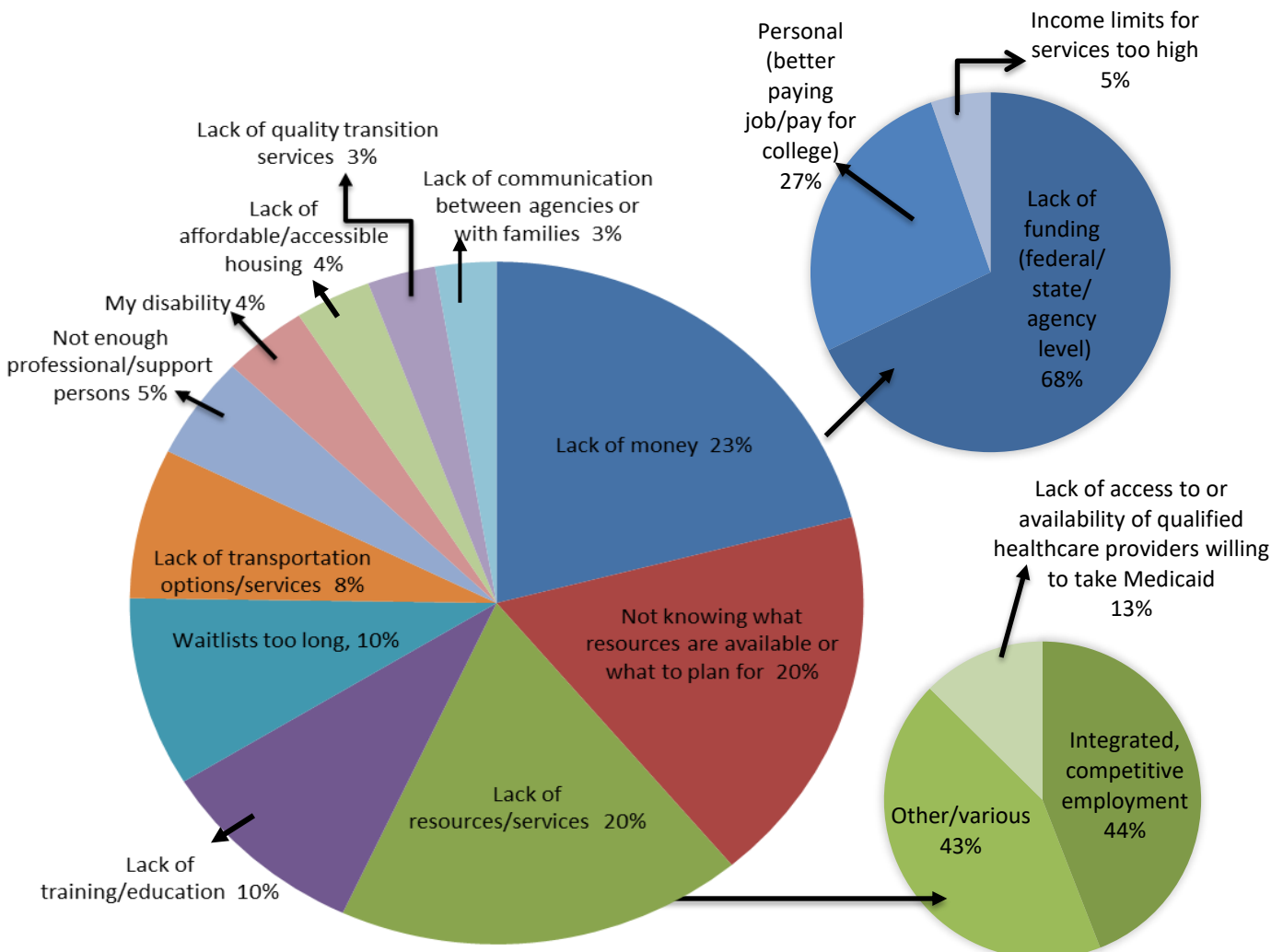
The top 3 Areas of Emphasis in the DD Act:      The top 3 areas needed to achieve success:

- ✚ Access to Services
- ✚ Education/Training
- ✚ Health

- ✚ Better job
- ✚ Better transportation
- ✚ Better social opportunities

Top barriers to achieving success (noted in the graph below):

- ✚ Lack of money (Federal/state/agency funding, better paying job, etc.)
- ✚ Not knowing what resources are available or what to plan for.
- ✚ Lack of resources/services (employment, qualified healthcare, etc.)



The findings led to the three goals (listed below), which are broken down further through twelve objectives and over 30 activities. Results from our survey and our complete five-year state plan can be found on our website: [www.nevadaddcouncil.org](http://www.nevadaddcouncil.org)

**GOAL 1:** Increase and strengthen the knowledge of individuals with I/DD to promote/encourage informed decision making about their choices leading to improved quality of life, increased independence, productivity and full inclusion in their communities.

**GOAL 2:** Ensure individuals with I/DD have the education and training necessary to participate in advocacy and policy making activities.

**GOAL 3:** In conjunction with individuals with intellectual and developmental disabilities and community entities, develop and strengthen systems that improve quality of services and access to quality services and supports in their local communities.

## 2019 LEGISLATIVE INITIATIVES

It is critical that state and local governments adhere to the principles established by landmark legislation for people with disabilities – the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). Both of these laws embody the central values expressed in the I/DD and Bill of Rights Act:

*“Disability is a natural part of the human experience that does not diminish the right of individuals with I/DD to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”*

To further the promise of the Americans with Disabilities Act and the U.S. Supreme Court’s Olmstead decision, programs which provide supports and services must be aligned with the principles of encouraging and supporting non-discrimination, full, meaningful inclusion in community life and economic self-sufficiency. These are the benchmarks that lead to a self-determined, tax paying, contributing member of society.

Councils are authorized under the DD Act to “educate,” “advise” or “inform” Federal, State and local policymakers. The “policymakers” referred to in the statute include members of Congress, officials of the Federal executive branch, Governors, members of State legislatures and staff of State agencies.

## COUNCIL POSITION STATEMENTS

The foundation for our 2019 Policy Priorities is built on our Federal mandates, mission statement, current policies and position statements.

### 1) HEALTH CARE

Individuals with I/DD are more likely to experience early death, chronic conditions, and preventable health conditions, compared to persons without disabilities. Even with access to care, people with I/DD often have difficulty recognizing and communicating their own health care needs. Moreover, there is a significant shortage of qualified, trained health care professionals who are prepared and willing to treat them.

NGCDD believes that comprehensive health care must provide affordable health care coverage, improved quality, and better cost control, while addressing the significant health and health care disparities faced by individuals with developmental disabilities. In addition to improving access to quality medical care for persons with developmental disabilities, the health care system must improve the way our State provides long term services and supports related to health care (such as assistance and supervision with activities of daily living, taking medication, and preparing meals).

#### Policy Recommendations:

Comprehensive health care must adequately address the following:

- *Access to affordable health care coverage for Nevadans with developmental disabilities, removing any bias based on pre-existing conditions, congenital impairments, or whether the intervention is habilitative or rehabilitative in nature.*
- *Assure greater access to quality care by health care providers trained to meet the medical needs of individuals with developmental disabilities.*
- *Provide appropriate, accessible health care for individuals with developmental disabilities.*
- *Ensure all policies and programs result in the creation of equal treatment in health-related services to all individuals.*
- *Encourage inclusion of individuals with I/DD in prevention and wellness programs.*
- *Develop and strengthen the “medical home” model to meet the health care needs of individuals with developmental disabilities.*

## 2) COMMUNITY SUPPORT

Over 5.4 million children and adults have developmental disabilities, and most of them live at home with families. However, they often receive too few, if any, services and face long waiting lists for needed supports. NGCDD believes that people with I/DD should receive community supports to allow them to live in the setting of their choice to enable them to participate fully in their community life. Children with I/DD should remain with their family or an alternative family model and receive the necessary supports to enhance community living.

### Policy Recommendations:

- *Change state services and programs to reflect the preference for community based services versus institutional living.*
- *Address inequities in access to and funding for direct support caregiver services for all disability populations; including increasing wages for direct support professionals to create a more stable and qualified workforce.*
- *Ensure the availability of respite care for families with members of all ages and disabilities.*
- *Promote the use of special needs trusts to financially assist families with disability related expenses to empower people with I/DD to become more self-sufficient and promote the use of asset development.*
- *Remove waiting lists for community living options by increasing financial and other supportive resources.*
- *Ensure the rapid movement of individuals with I/DD from institutions to community options with necessary supports and the transfer of the individuals' funds to the community programs.*

## 3) TRANSPORTATION

Within our society, freedom of movement is a fundamental right. However, it remains a largely unfulfilled promise for citizens with disabilities. Millions of Americans with I/DD have difficulties obtaining transportation that serves as a vital lifeline to employment, education, health care and community life.

NGCDD believes that all publicly funded and/or regulated transportation service systems must be: seamlessly coordinated among all modes of transportation; expanded in suburban, urban, rural and unincorporated areas to connect places people live with places they work, shop, socialize, worship, attend school, access health care, etc.; incorporated with mobility management and training services for individuals with developmental disabilities; designed to appropriately address insurance and liability of vehicles and operators who serve in a coordinated transportation environment, including non-profit providers); based on principles of universal design; supported by stable and adequate funding; and fully accessible to all people with developmental disabilities.

### Policy Recommendations:

- *Increase funding for mass transit programs (including paratransit).*
- *Encourage pooled use of vehicles purchased so that underutilized vehicles may be shared.*
- *Simplify the coordinated planning process for the programs that serve people with I/DD and create transparency and accountability.*
- *Promote incentives that encourage greater mobility for people with developmental disabilities.*
- *Advocate that transportation providers to have up to 15% of their fleet include accessible vans/taxi cabs – and require training for drivers on how to assist passenger with developmental disabilities.*
- *Support coordinated human services and public transportation planning process and its structure.*
- *Encourage use of uniform data collection to evaluate customer satisfaction and to support coordination of transportation efforts.*

## **4) ACCESSIBILITY**

Accessibility involves much more than providing ramps, it is the key element of inclusion and the baseline of equal service. Accessibility refers to the design of environments, products, and services that facilitate access for people with I/DD to the same level of independence and privacy as anyone else. Ensuring effective access to information and services isn't only about meeting legal requirements or satisfying a policy checklist - it is about constantly striving to expand meaningful participation for all. Providing equal access to all individuals with disabilities is the key element of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1992 (ADA). The ADA provides a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities, requiring State and local governments communicate as effectively with people who have I/DD as someone without.

The NGCDD supports and promotes the right of individuals with I/DD to meaningful participation and equal access to information, products and services through universal, accessible design. The NGCDD's current 5-year state plan addresses accessibility under Goal 1, Objective 1.4: Administration on Intellectual Developmental Disabilities Partners will collaborate to train a minimum of 20 persons per year to become knowledgeable on how to create accessible materials, media and websites, thereby; increasing the number of persons with I/DD that have access to important information.

### Policy Recommendations:

- *Promote the inclusion of accessible technologies, and the need for universal, accessible design through education and practices that dispel the myths and misguided understanding of what accessibility is and is not.*
- *Promote equal access to services and environments by encouraging the adoption of universal design principles and implementing accessible, inclusive practices into all aspects of public engagement.*

- *Work with the Nevada Legislature and the State of Nevada to mandate training for all State of Nevada employees on the need for accessibility as well as how to create and maintain accessible content.*
- *Work with the Nevada Legislature and the State of Nevada to mandate the development of inclusive public meeting protocols across all state entities and require training for state employees on approaches.*
- *Work with the Nevada Legislature and the State of Nevada to mandate a review of procedures and policies to ensure they are consistent with inclusive and accessible goals.*

## **5) GUARDIANSHIP AND SUPPORTED DECISION MAKING**

Guardianship is a legal proceeding that can remove civil rights and privileges of an individual by assigning control of his or her life, or aspects of their life to someone else.

Many options, other than guardianship, are available to provide counsel, guidance and assistance with making decisions. The principles of Informed Choice, Person Centered Planning and Self-Determination dictate that adults with intellectual/I/DD(I/DD) are respected and supported in making their own life decisions. Individuals who can make life decisions with support from others around them should be enabled to do so.

Supported decision-making is recognized as a less restrictive alternative to guardianship; whereby, trusted supporters are afforded the legal status to be with the adult, participate in discussions, help gather and evaluate information, consider and communicate decisions so individuals with I/DD understand the situations and choices they face and can make their own decisions without the need for a guardian.

The Nevada Governor's Council on I/DD supports the rights of individuals with I/DD to direct their own lives to the maximum of their abilities through changes to the guardianship system in Nevada that promotes the best practices of Person Centered Planning, Informed Choice and Self Determination through Supported Decision Making.

### Policy Recommendations:

- *Empower individuals by applying the principles of Self-Determination, Informed Choice and Person-Centered practices in all aspects of their life.*
- *Educational and training material about alternatives to guardianship should be provided to people with I/DD, trusted supporters, educational, medical, financial, legal, and other professionals in order to ensure consistency and opportunity across the state.*
- *Support legislation that promotes Supported Decision-Making options to be considered as alternatives to guardianship.*



## 6) EMPLOYMENT

Working age people with developmental and other disabilities are among the most unemployed and underemployed segments of our society. Too often, unemployment is often accepted as an inevitable result of living with a significant developmental disability. Employment is the avenue to independence and increased socialization for individuals with developmental disabilities.

The Nevada Governor' Council on I/DD(NGCDD) believes that individuals with I/DD who can and want to work should have access to the resources and supports necessary to gain and maintain meaningful community-based employment.

### Policy Recommendations:

- *Remove barriers that create disincentives for people with I/DD to find and maintain competitive employment (employment includes supported employment, job training and job coaching) with competitive wages in the community. These barriers may include: transportation, flexible options for on the job supports, and continued or potential health care benefits.*
- *Implement "Employment First" policies that transform the expectations of state agencies, service providers and people with developmental disabilities. Under "Employment First", the expectation is that a person with a developmental or other disability can and wants to work, and a successful outcome is finding these individuals meaningful and gainful employment that meets their needs and interests by tailoring services to help them succeed in the workforce.*
- *Fully fund the state vocational rehabilitation (VR) program that are significantly underfunded to meet the employment needs of individuals with severe disabilities who need VR services to obtain employment.*
- *Engage the private sector to raise awareness about and support for inclusion of people with I/DD in the workforce and provide training, incentives and other supports to the business community to increase hiring of people with developmental disabilities.*
- *Increase, maintain, or reallocate funding for transition to work programs that successfully assist young people with I/DD as they age out of education settings and prepare to seek, gain and maintain meaningful employment. Increase accountability at the local level to assure that students have jobs when they graduate.*
- *Strengthen funding for self-employment initiatives that enable people with I/DD to start their own businesses and/or be self-employed.*
- *Adopt proactive policies by federal, state and local government agencies to recruit, hire, train and mentor people with developmental disabilities.*
- *Provide incentives to employers to support integrated, community employment at minimum wage or above.*

## 7) HOUSING

Across the nation, people with I/DD face a severe crisis in the availability of decent, safe, affordable and accessible housing. Nevada continues to promote inclusion for people with I/DD to live in their communities and guard against return to congregate facilities or other institutions. NGCDD believes that citizens with I/DD should live in inclusive, safe and affordable communities of their choice and be provided with the needed individualized supports and accommodations.

### Policy Recommendations:

- *Increase the supply of affordable and accessible housing options that are integrated in the community, including temporary housing, rental housing and/or home ownership, to meet the growing unmet needs of people with disabilities and their families.*
- *Significantly increase funding for and protect the integrity of HUD programs, U.S. Department of Agriculture housing programs, as well as all other federal/state housing programs providing funding for people with disabilities.*
- *Provide funding to address the need for safe, affordable and accessible emergency housing for individuals with disabilities.*
- *Remove barriers that prevent people from temporary housing, rental housing, or buying their own homes.*
- *Require that projects developed with public funds and apply design standards identical to those in Section 504 of the Rehabilitation Act.*
- *Eliminate discrimination based on disabilities in all sales, rental, and other non-assisted living accommodations.*
- *Encourage adoption of universal design as new units are built or remodeled to include key financing stakeholders.*

## 8) QUALITY ASSURANCE

Quality assurance is a confirmation of whether or not products or services meet or exceed customer expectations. Quality Assurance involves advocacy, capacity building, and systemic change activities resulting in improved choice in consumer and family-centered services for individuals with developmental disabilities. Quality Assurance activities include interagency coordination and collection of data resulting in improved services, supports, and other assistance. Such activities promote self-determination, independence, productivity, and inclusion in all aspects of community life for individuals with developmental disabilities.

NGCDD believes individuals with developmental disabilities must define their own quality of life/services. All service systems, such as education, employment, health, housing, child care, recreation, transportation, and any other system that impacts persons with developmental

disabilities, should actively engage these individuals and their families in quality assurance. This includes identifying problems and making improvements that enhance the quality of life for people with developmental disabilities.

Policy Recommendations:

- *Support compliance with all laws, certification requirements, licensing standards, and contractual obligations.*
  - *Promote and support individuals to find and maintain relationships with people in their communities beyond paid providers and caregivers.*
  - *Ensure access to home and community-based services and supports that are planned and implemented in keeping with each individual's unique needs, expressed preferences, and decisions concerning his/her life in the community.*
  - *Empower individuals by embracing the principles of self-determination and applying person centered practices.*
  - *Demand statewide Quality Assurance information management systems that assist in collection, tracking, trending, and analysis of meaningful personal outcomes.*
  - *Ensure access to information and supports necessary to affect public policy at the local, state, and national levels.*
-